

**STATE OF COLORADO**  
**STATEWIDE COORDINATED STATEMENT OF NEED**  
**(SCSN)**

**Colorado Department of Public Health and Environment**  
**Title II Ryan White CARE Act Program**

**January 31, 2006**

**STATE OF COLORADO  
STATEWIDE COORDINATED STATEMENT OF NEED (SCSN)**

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# STATE OF COLORADO

## STATEWIDE COORDINATED STATEMENT OF NEED (SCSN)

### 1. PURPOSE

*The purpose of the Statewide Coordinated Statement of Need is to provide a collaborative mechanism to identify and address significant HIV care issues related to the needs of people living with HIV/AIDS (PLWH/A), and to maximize coordination, integration, and effective linkages across the CARE Act Titles related to such issues.*

### 2. GOALS IN DEVELOPING COLORADO'S SCSN

The intent of the SCSN is to provide an overarching framework that defines priority directions for programs that serve persons living with HIV/AIDS. As part of this framework, crosscutting issues have been identified that influence the coordination among service providers both within and outside of the Ryan White CARE Act program. Emerging trends, service gaps and areas of unmet need have been profiled.

Colorado's Statewide Coordinated Statement of Need (SCSN) meets requirements from the Health Resources and Services Administration (HRSA) that all providers of services to persons living with HIV/AIDS (PLWH/As), especially those funded under the Ryan White CARE Act, work to enhance the coordination of their services.<sup>1</sup>

The process followed to develop the SCSN has been broadly representative and has included participation from program representatives from all Ryan White Titles, CARE Act providers and funders of service.

### 3. MOST RECENT STATE HIV/AIDS EPIDEMIOLOGICAL PROFILE

As detailed later in Appendix E, a number of different sources of information have been used to identify emerging trends related to HIV/AIDS in Colorado. In addition, on November 7, 2005, stakeholders representing Colorado's HIV/AIDS community were convened to identify emerging trends that will influence the delivery of HIV services over the next three to five years.

Participants in this process highlighted a number of emerging trends of significance. These are further confirmed by statistics from the Colorado Department of Public Health and Environment's *HIV & AIDS in Colorado*.<sup>2</sup> Information regarding emerging trends was also compiled from the most recent Title I Comprehensive Plan, the 2005 Title I Needs Assessment report, as well as from needs assessment material compiled by the Research and Evaluation Unit

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<sup>1</sup> As required in reauthorization language in the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act Amendment of 1996 (Public Law 101-38), Title XXVI of the Public Health Service Act (42 U.S.C. 300ff-11 *et. seq.*)

<sup>2</sup> Colorado Department of Public Health and Environment (2005) *HIV & AIDS in Colorado*, Integrated Epidemiologic Profile of HIV and AIDS Prevention and Care Planning reported through June 2004.

of the Colorado Department of Public Health and Environment. Key trends are detailed below.

### **3.1. Changes in Who is Infected<sup>3</sup>**

Stakeholders and service providers from Colorado's HIV community have observed that the face of those with HIV/AIDS is changing as the epidemic differentially affects people of color, women and substance abusers. Increasingly, providers note that those newly infected with HIV also suffer from co-occurring disorders (mental illness, substance abuse, and hepatitis C), factors that complicate the types of treatments and service coordination that are required.

As the profile of those infected with HIV/AIDS is changing, providers perceive concomitant changes in the ways in which services are sought. They believe that care seeking is increasingly being driven by medical crises, especially among those who know their HIV status, but who are not in care. Delays in seeking care are evident within the Denver Eligible Metropolitan Area, where 47% of the 383 newly diagnosed cases in 2004 were AIDS cases. Populations at special risk for delays in seeking care are African-Americans, pregnant women, at-risk youth and undocumented immigrants.

At the 11/7 Roundtable Consensus meeting, stakeholders recommended that education and outreach efforts in Colorado can benefit from more aggressive and non-traditional marketing strategies to reach those most at risk, focusing in particular on those who are infected but not in care. Messages should be crafted that address underlying self-esteem problems or "not caring" attitudes and be selectively targeted toward different at-risk populations such as women, people of color and youth. Prevention and treatment outreach should also focus on the needs of the incarcerated population, both in prisons/jails and upon their reentry into the community. Finally, efforts need to be made to strengthen the link between prevention and treatment providers. Delays in treatment are costly, so, too are failures in disseminating effective prevention messages and strategies.

From the recent epidemiological profile prepared by the Colorado Department of Public Health, the following epidemiological trends have been noted. (See Appendix A for further details on epidemiological trends.)

While newly diagnosed AIDS cases have remained stable over the past five years, cases of HIV have increased by 15%, either because of changes in testing efforts, increases in infection rates or both.

The HIV epidemic in Colorado continues to consist primarily of men who have sex with men (MSM) and men who have sex with men who are also injection

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<sup>3</sup> Summary statements in this section were developed during the 11/7 Consensus Roundtable Meeting attended by 23 attendees representing all Ryan White Titles, ADAP, the Governor's AIDS Council, key service providers and consumers.

drug users (MSM/IDUs). Together these groups comprise over 75% of the cumulative cases of HIV and AIDS (or 10,979 cases).

Females represent an increasing proportion of newly diagnosed HIV cases, now accounting for 10% of persons living with HIV and AIDS (or 940 cases). Whereas females represented only 5% of AIDS cases between 1985 and 1989, the proportion of women with AIDS has increased to 16% between 1999 and 2003.

Racial differences among females are even more profound. The HIV rate for Black females (19.1/100,000) is over 24 times that in White females (0.8/100,000).

People of color are over represented in the HIV epidemic of HIV/AIDS, particularly among recently infected persons. Rates of HIV infection among African-Americans are four times those of Whites while the HIV rate for Hispanics is one and a half times that of Whites.

Over a third (37%) of newly diagnosed cases in 2003 were 30-39 years old, while 30% were 20-29. Men who have sex with men between the ages of 30-39 continue to be over represented among newly diagnosed cases of HIV.

Injection drug users (IDUs) represent 10% of the total HIV/AIDS cases reported in Colorado, a 23% increase over the past five years.

The importance of these trends was confirmed by a survey distributed extensively throughout Colorado's HIV/AIDS community. Trends related to sub-groups at particular risk for infection, late diagnosis and lack of care are highlighted in the Table 1 below.

**Table 1: Trends in Who is Infected**

N= 195	Important Emerging Trend	Somewhat Important	Not an Issue in Colorado
<b>WHO IS INFECTED?</b>			
Increases in infection among minorities	84.9%	14.5%	5.0%
Increases in infection among women	76.6%	21.8%	1.6%
Increased incidence of dual diagnosis	75.5%	23.9%	5.0%
Late diagnosis	70.7%	29.3%	0.0%
Persons who know their status but are not in care (Unmet need)	70.1%	26.7%	3.2%
Increased incidence of young gay men with HIV infection	68.4%	29.4%	2.1%

See Appendix E for information on the source of this survey information.

Within the Denver Title I program, similar epidemiological trends have been highlighted. The following represent ways in which the HIV epidemic is changing within the Denver Eligible Metropolitan Area.<sup>4</sup>

- Among those who were newly diagnosed with HIV in 2004 (N=383), people of color (both Blacks/African Americans and Latinos) represent a disproportionate number of the newly diagnosed. Blacks/African Americans, who comprise 5.4% of the general DEMA population, represented 20.4% of those newly diagnosed in 2004. Latinos, who comprise 19% of the general DEMA population, represented 21.4%, respectively.
- The proportion of women living with HIV is increasing. In 2004, 11.7% of those newly diagnosed with HIV/AIDS were women.
- Other counties in the DEMA (besides Denver) are seeing an increase in HIV/AIDS cases; 14.1% of newly diagnosed cases were in Arapahoe County; 9.1% in Jefferson County; and 6.3% in Adams County.

Other trends of significance within the Denver Eligible Metropolitan Area are:

- The majority of HIV/AIDS cases in the DEMA (70.8%) are PLWH/A 45 years of age and older.
- In terms of risk behavior, men who have sex with men (MSM) continue to make up the majority of newly diagnosed cases (58%) in the DEMA
- Denver had the number 1 ranking (15%) of AIDS incidence (number of new cases of AIDS diagnosed each year) for MSM-IDU in 2004 epidemiological data produced by CDC.

### **3.2 Changes in the Service Needs of PLWH/As<sup>5</sup>**

At the 11/7 Roundtable Consensus meeting, service providers commented they are finding that compared to previous clients, current PLWH/As have needs for basic services such as housing and transportation. Poverty and the concomitant life struggles associated with it can be overwhelming and cause care seeking to have lower priority among certain high-risk groups. Providers also note that when PLWH/As do seek treatment, they tend to be sicker than in the past and are more likely to have co-morbid conditions such as mental illness, substance abuse and hepatitis C.

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<sup>4</sup> Evaluation and Assessment Committee (2006) 2006-2008 COMPREHENSIVE PLAN, RYAN WHITE TITLE I DENVER ELIGIBLE METROPOLITAN AREA, Denver HIV Resources Planning Council in conjunction with the Mayor's Office of HIV Resources, Draft: November 2, 2006.

<sup>5</sup> Summary statements in this section were developed during the 11/7 Consensus Roundtable Meeting attended by 23 attendees representing all Ryan White Titles, ADAP, the Governor's AIDS Council, key service providers and consumers.

According to representatives at the 11/7 Roundtable Consensus meeting, PLWH/As struggle with mental illness and substance abuse problems, issues that complicate their interest in seeking treatment, remaining adherent to their medications and practicing prevention options. Mental health and substance abuse are interrelated since many of those with mental illness “self-medicate” themselves with drugs. The widespread use of methamphetamine poses particular prevention challenges as it reduces the chance that HIV prevention strategies will be used. While Coloradoans have been reported to have high rates of drug use, government support for substance abuse programs is low, resulting in high costs associated with untreated substance abuse. Unless these mental health and substance abuse issues are addressed, the motivation of PLWH/As to seek HIV treatment will remain as a lower priority. Hence coordination among mental health, substance abuse and HIV providers must be paramount.

At a time when the challenges of serving the PLWH/A population are becoming more difficult, the Roundtable Consensus participants believe that some communities have become complacent about the epidemic, especially in rural areas. Non-traditional strategies will be required to strengthen and more adequately fund prevention efforts. At the state level, mental health, substance abuse and HIV agencies should work to encourage collaboration among providers at the community level. Competition for limited funds should be minimized where possible. Attention should also be given to the chronic need for more mental health providers.

**Table 2: Service Delivery Challenges**

N=195	Important Emerging Trend	Somewhat important	Not an Issue in Colorado
<b>SERVICE DELIVERY CHALLENGES</b>			
Increased economic challenges	80.0%	18.4%	1.6%
Barriers to care for underserved populations	78.9%	19.5%	1.6%
Linkages with prevention	68.7%	30.2%	1.1%
Unmet need and gaps in CORE services for persons both “in” and “out” of care	67.6%	30.8%	1.6%
Increasing access to medications (prescription drugs)	64.0%	29.6%	6.5%
Need for dental care	61.5%	35.3%	3.2%
Housing	60.4%	38.0%	1.6%
Increasing coordination of services (e.g., coordination between Title II and III)	56.0%	42.9%	1.1%
Access and adherence to medications while incarcerated	53.3%	35.7%	11.0%
Improving CARE entry and access points	51.9%	44.8%	3.3%

See Appendix E for information on the source of this survey information.



A trend of particular significance for providers who serve people living with HIV/AIDS has been the increases in the number of clients who have been accessing Ryan White primary care services. Within the Title I program, there has been a consistent 9% year-over-year increase in the number of people accessing Ryan White primary care services (see table below). At the same time funds available to support these services have remained constant since 1999.

**Table 3: Trends in Use of Primary Care Services**

Year	Primary Care Client Count	Percentage Increase
2004	2341	9.3%
2003	2180	9.0%
2002	1970	8.9%
2001	1756	--

#### **4. DESCRIPTION OF IDENTIFIED GAPS AND/OR OVERLAPS IN SERVICE**

Differences in perspectives between providers and consumers are evident in the ways in which each group ranked the core services where there are gaps or unmet needs. The results of the SCSN survey show that a majority of PLWH/As ranked “prescription drugs” and “primary care” as the core services where needs are unmet, whereas other respondents (providers, community advocates, agency staff) focused on the importance of “mental health” and “substance abuse services” as areas of unmet need.

**Table 4: Comparison Ranking of Core Services with Unmet Needs, Providers and Consumers**

CORE SERVICES- Rank the top five priority areas From 1 to 5. Select only 5 areas	PLWH/As N=29 % ranked in top 5	All OTHERS N=165 % ranked in top 5
Prescription drugs	69%	56%
Primary care	55%	52%
Dental care	48%	41%
Mental health	41%	76%
Case management	41%	40%
Emergency housing assistance	41%	47%
Health insurance continuation	41%	50%
Emergency financial aid	28%	40%
Substance abuse services	28%	66%
Client advocacy	28%	24%
Food bank	21%	14%
Transportation	17%	28%
Home health care	17%	17%
Hospice	3%	12%
Other:	3%	3%

The Title I Needs Assessment provides further information on areas of unmet need.<sup>6</sup> The Denver Title I area covers the metropolitan counties of Arapahoe, Adams, Denver, Douglas and Jefferson. A specific focus of the 2004 needs assessment was to survey persons living with HIV/AIDS (PLWH/A) who are “*aware of the HIV status and not in care*” and to determine their unmet needs. Persons out of care were defined as those who had not accessed primary medical care for more than a year or who had never accessed primary medical care.

Surveys for the “in-care” and “out-of-care” populations were conducted during the fall of 2004. In all, surveys were returned by 311 “in-care” PLWH/As (or 13% of all persons in-care). Out-of-care surveys were completed by 158 “out-of-care” PLWH/As. Of these, 54 (or 34%) were completed by persons who had never been in care. It is estimated that the out-of-care surveys were returned by 8% of PLWH/As who had not received services in the past 12 months.

Table 5 below summarizes the top five service areas ranked by clients responding to the 2003 and 2005 surveys of PLWH/As in the Title I area. While the rankings vary from year to year and from survey to survey, “prescription drugs” and “primary care” remain high among the most needed services. Within the Title I area, PLWH/As also ranked “dental care” and “food bank” as among the top three most needed services. Some of these differences may be attributed to the particular efforts made to distribute the survey among PLWH/As who are not in care whose service needs may vary from those who are in care.

**Table 5: Ranking of “Most Needed” Services, Title I Needs Assessment**

Service Category	2005 Survey	2003 Survey
Dental Care	1	6
Primary Medical Care	2	2
Food Bank	3	4
Prescription Drug	4	1
Case Management	5	3

## **5. LIST OF PRIORITIES IDENTIFIED, INCLUDING PRIORITIES ADDRESSING UNMET NEED AND GAPS IN CORE SERVICES**

### **5.1. What Do we Know About Unmet Need in Colorado?**

Recognizing the importance of reaching persons living with HIV/AIDS who are not in care, several different attempts have been made to estimate the size of this population.

<sup>6</sup> Conducted during the fall of 2004 within the Denver Eligible Metro Area (DEMA) [Title I].

## **Unmet Need among Priority Risk Populations in Colorado – Persons with HIV who have not Been Tested**

Within the Title II Ryan White program, the definition of need is based on estimates of the number and percent of: (a) PLWH/non-AIDS aware, and (b) PLWA who did *not* receive HIV primary medical care during the same 12-month time period.

Estimates of those who are infected but not aware of their status are difficult to derive. The Centers for Disease Control and Prevention estimate that for every three people who know they are infected with HIV there is one person who does not. Using this estimation technique, the number of Coloradoans who are actually infected with HIV could be as high as 13,575.<sup>7</sup> Of these, 3,394 are persons with HIV/AIDS who have not yet been officially diagnosed.

## **Unmet Need in the Denver Eligible Metropolitan Area – Persons Who Have Been Tested, But Are Not Receiving Primary Care Services**

The Ryan White Title I program currently funds primary care services for 2,341 clients, as determined through the CAREWare client tracking system. Primary care services within the Title I program are provided at three facilities: Denver Health, University Hospital and Children’s Hospital. In addition, there are an estimated 2,900 PLWH/As who are not eligible for Title I services, but receive primary care that is provided/funded through the Veteran’s Administration, Rose Hospital, Kaiser, and other private insurers.

Out of a total 7,251 PLWH/As in the Title I area, the number of persons “out of care” is estimated to be 2,010 or 28% of the all PLWH/As living in the Denver metro area. These are individuals who had no CD4, viral load, or ART in the past 12 months.<sup>8</sup>

### **Characteristics of Those Not In Care**

As part of the Title I Needs Assessment process, particular efforts were made to identify PLWH/As not currently in care through flyers distributed at consumer points-of-contact, including food banks, bars, HIV case managers offices and homeless shelters. Table 5 provides a profile of the out-of-care PLWH/As who responded to the survey. These results provide a preliminary perspective on those who are “out of care.”

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<sup>7</sup> There were 10,181 HIV/AIDS cases in Colorado through 3/2004. If there were 1 person infected, but unaware of their status for every 3 people who have been diagnosed, then the total number of HIV/AIDS cases in Colorado would be 13,575.

<sup>8</sup> Denver HIV Resources Planning Council (2005) *2005 Needs Assessment Summary*. Denver, Colorado.

**Table 6: Profile of Out-Of-Care Survey Respondents, Title I Needs Assessment**

PLWH/A Profile	Out-of-Care Survey Respondents	Total PLWH/A in the Denver Eligible Metro Area
GENDER:	Male	85%
	Female	15%
RACE/ETHNICITY:	Black	30%
	White	47%
	Hispanic	16%
	Native American	6%
		<1%
RISK BEHAVIOR:	MSM	7%
	IDU	25%
	MSM/IDU	8%
	Heterosexual	20%
TOTAL N:	158	7,251

### 5.2. What are the Next Steps for Addressing Unmet Need and Gaps in Core Services?<sup>9</sup>

Within Colorado’s HIV/AIDS community, the Roundtable Consensus Meeting participants concluded that more effective strategies need to be deployed to develop valid needs assessments that identify the needs of PLWH/As who are both in care, diagnosed but out of care and those who do not know their status. As a first step, more precise definitions of the PLWH/A population who are underserved need to be agreed upon. Needs assessment strategies will be enhanced when consumers are actively involved in the planning and implementation of any data collection efforts. *Consumer defined needs should be first and foremost in any needs assessment effort.*

Approaches for improving needs assessment are listed below:

1. Use client-focused data collection strategies. Street interviews may be more labor-intensive and expensive, but can supplement traditional survey methods.
2. Develop client-friendly ways of collecting data. Data collection instruments should use terms that clients can understand. Incorporate cultural competence principles in all data collection strategies. Ensure that instruments are translated for non-English speaking populations.
3. Collect data through existing sources of care such as case managers, outreach workers.
4. Collect data through multiple data collection methods including quantitative and qualitative approaches such as surveys, in-depth interviews with probing questions. Incorporate legitimate sampling techniques.

<sup>9</sup> Summary statements in this section were developed during the 11/7 Consensus Roundtable Meeting attended by 23 attendees representing all Ryan White Titles, ADAP, the Governor’s AIDS Council, key service providers and consumers.

5. Seek multiple points of view and understand the impact on contextual or community factors on issues such as access and use of services.
6. Provide incentives to consumers to participate in needs assessments such as gift certificates, gift cards and transportation help.
7. Examine survey results from different perspectives including various types of providers and subpopulations of clients.
8. Build strategies from what has worked in the past, continuing to improve and refine needs assessment data collection strategies.

An important dimension of future needs assessment work will be to develop effective strategies for identifying *PLWH/As who know their status but do not access care*. Some alternative strategies to be pursued are:

- Capture PLWH/As at the end of the month -- before they receive their monthly monies.
- Interview “positive” gay men at the beer bus, providing an entrance fee to this.
- Link data collection with the receipt of primary medical care. (This strategy would work better in a tight knit community such as a rural area and is less likely to be effective in an urban setting.)
- Use patient self-management to let patients know their medical history and diagnosis and in turn increase their engagement in their own care.

<b>6. DESCRIPTION OF PRIORITIES ADDRESSING IDENTIFIED BARRIERS TO CARE FOR UNDERSERVED POPULATIONS IN THE STATE</b>
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As part of the SCSN survey, over 800 comments were received regarding unmet need for service, service gaps and barriers to care. The top five barriers to care identified by the respondents are listed in Table 6 below. They focus on financial issues, the need for mental health, substance abuse and medical services, as well as the requirement for better coordination and collaboration among service providers. Other comments focused on the need for life support services including housing, insurance, transportation, employment, outreach and case management.

**Table 7: Number of Comments regarding Unmet Need and Barriers to Care, SCSN Survey**

N= 801

Financial	75	9%
Mental Health	72	9%
Substance Abuse	66	8%
Medical	63	8%
Coordination/Collaboration	59	7%

**Services Needed to Bring “Out-of-Care” PLWH/A into Care**

Information on services needed by those “out-of-care” was also collected through the Title I Needs Assessment data collection efforts. In the table below, the out-of-care survey respondents indicated which services would help them to get to a doctor. Two

separate service rankings are provided: 1) for those survey respondents who have been in and out of care, and 2) for those who have never been in care.

**Table 8: Outreach Strategies for Out-of-Care PLWH/As, Title I Needs Assessment**

SERVICE RANKING TO HELP SEE AN MD	PLWH/As who have been in and out of care	PLWH/As who have never been in care
Peer Counseling	1	1
Case Management	2	2
Housing	3	4
Counseling on Side Effects of HIV Medications	4	5
Substance Abuse Counseling	5	3
Mental Health Counseling		5

*Title I Needs Assessment, 2005*

### **Options for Improving Access to Care for Special Needs Populations**

To identify how different special needs populations experience barriers to care, the Research and Evaluation Unit of the Colorado Department of Public Health and Environment compiled a comprehensive review between 2003 and 2004. Data were collected through consumer and provider surveys, focus groups and one-on-one interviews. This work (summarized below) highlights the importance of considering barriers to care from the perspective of different at-risk populations, as summarized in Table 9 below.

The need for more integrated service programs that address substance abuse, mental health, and HIV care and prevention was a common theme as the needs of these specific groups were examined. Needed increases in re-entry programs for those being released from prison were also highlighted.

**Table 9: Barriers Experienced by Different At-Risk Groups**

	Women At Risk	Men who Have Sex with Men	Injection Drug Users	The Formerly Incarcerated
Risk Behaviors and Other Factors Influencing Risk Behaviors	Unprotected sex with multiple sex partners connected with alcohol and drug use	Unprotected anal sex connected with alcohol and drug use  Disclosure issues	Sharing needles, and works and unprotected sex  Denial of risk  Coexisting addiction, mental illness and other challenges	Injection drug use and sharing of needles is common
Barriers	Services are Inaccessible or Inappropriate  Lack of Substance Abuse Treatment  Failure to Deal with Mental Health Issues  Not knowing where to go, cost, transportation and child care issues	Barriers to condom use  Tailor prevention to individual needs  Privacy concerns	Lack of trust Lack of access to childcare  Costs and failure to address mental health and other life concerns  Privacy concerns  Not knowing where to go	No programs tailored to their needs  Privacy concerns

**Options for Improving Barriers to Care by Service Category**

Additional information on barriers is available from the Denver Eligible Metropolitan Area where consumers were surveyed about barriers that are specific to different types of services, as part of the 2003 needs assessment previously described. The results, shown below, highlight the importance of cost and eligibility barriers, but also demonstrate that more could be done to enable consumers to be aware of the services that are available to them.<sup>10</sup>

<sup>10</sup> Evaluation and Assessment Committee, Denver HIV Resources Planning Council (2006). *2006-2008 Comprehensive Plan Ryan White Title I, Denver Eligible Metropolitan Area*. Developed in conjunction with the Mayor’s Office of HIV Resources. Denver, Colorado.

**Table 10: Barriers to Care – Denver Eligible Metropolitan Area**

Service	Reason 1	Reason 2	Reason 3
Dental Care	Cost - 20 (43.5%)	Don't know where to go - 14 (30.4%)	Did not know it was offered - 11 (23.9%)
Emergency Housing Assistance	Not eligible - 15 (46.9%)	Don't know where to go - 7 (21.9%)	Cost - 4 (12.5%) Did not know where to go - 4 (12.5%)
Insurance Continuation	Not eligible - 10 (40%)	Cost - 7 (28%)	Did not know it was offered - 7 (28%)
Substance Abuse Treatment	Did not know it was offered - 10 (43.5%)	Transportation - 6 (26.1%)	Don't know where to go - 6 (26.1%)
Emergency Financial Assistance	Not eligible - 7 (30.4%)	Did not know it was offered - 6 (26.1%)	Don't know where to go - 5 (21.7%)

## 7. CROSS-CUTTING ISSUES <sup>11</sup>

Colorado's *current system of services is difficult for clients to navigate*, according to program representatives from all Titles funded under the Ryan White CARE Act. Among survey respondents, the highest rated crosscutting issue was the need for improved coordination of services (17% of all responses.)

Participants at the 11/7 Roundtable Consensus Meeting concluded that the presence of many different agencies, some providing overlapping services, complicate how clients receive care. They suggested that agencies need to make additional efforts to maintain contact with clients and to track when they require follow up services, sharing client data and referral information across agencies. Better linkages should also be created between prevention and service programs.

According to the Roundtable Consensus Meeting attendees, agencies lack the capacity to coordinate client needs in areas such as adherence to medications, in part due to the confidentiality of client information. A lack of transportation options poses challenges as well. Additional barriers complicating efforts to create a more seamless system include:

- Unfunded mandates requiring that services be provided without any additional funds - Funding was among the top cross-cutting challenges noted by survey respondents (14% of all responses.)
- The absence of one-stop service centers that would improve access to services.

<sup>11</sup> Summary statements in this section were developed during the 11/7 Consensus Roundtable Meeting attended by 23 attendees representing all Ryan White Titles, ADAP, the Governor's AIDS Council, key service providers and consumers.



- Red tape that limits client access to needed services
- The marginalization of some clients, inhibiting their access to treatment and
- Communication patterns that are inappropriate for a client's educational level or cultural background.<sup>12</sup>

Coordination of services is a particular challenge for subgroups of PLWH/As including youth, women, minorities and people who are co-infected with HIV and hepatitis C. Agencies need to be more open with clients about the limitations of the current system while becoming creative about addressing them, developing programs that better fit the needs of individual clients.

Across all Titles, program staff have identified specific services where gaps and unmet need exist.

- Auxiliary Services such as substance abuse and mental health need to be incorporated into all programs serving PLWH/As, in particular to meet the needs of subpopulations who have not previously been receiving treatment.
- Clients have difficulty accessing housing, food, and financial assistance. Program representatives from all Titles need to provide better access to these services and encourage referrals across programs.
- Initiatives to enable clients to get back to work should be developed, including vocational training.

## **8. ACTION STEPS – CROSS-CUTTING ISSUES**

To address these challenges, representatives from all Titles funded under the Ryan White CARE Act recognize a need to share information regarding gaps in services and unmet need among PLWH/As. Four specific actions were recommended to enhance inter-Title collaboration in the future:

1. Work will be undertaken to create a consistent methodology for defining gaps and unmet needs in services.
2. The Title II program (Colorado Department of Public Health and Environment) will reconvene staff representing all Titles to plan for a statewide needs assessment. Others to be included will be representatives from *Coloradoans Working Together*, the Prevention Planning Council. Participation by consortium area staff throughout the state will help to ensure that differences between the urban and rural parts of the state are considered in the needs assessment process.
3. Staff from all Titles will share research information across programs. For example, when CDPHE does special research projects, these results will be available to other programs for review.

<sup>12</sup>

As identified at the 11/7 Roundtable Consensus Meeting.

4. Collaborative efforts will be undertaken to document what's working in the Title I, Title II, Title III, and ADAP programs, with efforts made to document and share "program successes."

Additional recommendations developed during the 11/7 Roundtable Consensus Meeting are listed below.

#### **9. RECOMMENDED NEXT STEPS - NEEDS ASSESSMENT**

More meetings across Titles and among HIV/AIDS service providers such as the group that was convened for the SCSN meeting

1. Better follow-up with patients identified as positive, but not following up to receive services.
2. Progress reports shared between and among program staff from different Titles.
3. Initiate trainings within and across Titles to improve outreach and access to services among PLWH/As, both those currently receiving services and those who are out of care.
4. Initiate work within our own programs to improve PLWH/A outreach, access and service delivery to all segments of the PLWH/A community.
5. Develop collaborative approaches to needs assessments and survey design that include community involvement.

#### **10. NEXT ACTION STEPS – EMERGING TRENDS**

1. Mandate HIV testing of pregnant women during routine physicals and at the time of delivery to prevent perinatal transmission of HIV.
2. Normalize HIV testing, encouraging use of the rapid testing and the new home testing options, but at the same time working to ensure that those who test positive are able to seek appropriate services.
3. Support the use of peer educators and patient advocates, especially in rural areas.
4. Use existing provider systems (e.g., rural doctors, public health department staff, home visiting case managers, outreach workers and emergency room personnel) to disseminate prevention messages among high-risk populations especially in rural areas.
5. Provide mental health and substance abuse providers with information regarding the prevention of HIV and hepatitis C, using a "train the trainer" model.
6. Support collaborations among community based agencies and non-traditional providers such as those working with refugees and the GLTB population.

## **11. OTHER RECOMMENDED ACTIONS – CROSSCUTTING ISSUES**

- Determine how to supplement Title II Care dollars with other funding sources such as prevention programs sponsored by the Centers for Disease Control (CDC), the National Institutes of Health (NIH) and the Substance Abuse and Mental Health Services Administration (SAMHSA).
- Work collaboratively with state mental health departments and service agencies, to identify non-Ryan White funding sources and to seek private and public support for the delivery of mental health services to PLWH/As.
- Use the 340B option to buy cheaper drugs, creating access for clients to gain access to non-ADAP formulary drugs.
- Coordinate efforts across agencies need to ensure that clients obtain the information and support they need to participate in the new Medicare Drug Plan Process under Medicare Part D.

## APPENDICES

### A. EPIDEMIOLOGIC PROFILE<sup>13</sup> (Comparison between March 2000 and June 2004)

2000	2004
In Colorado as well as nationally, fewer people are dying from AIDS and fewer people with HIV are progressing to AIDS as a result of new therapies. Prevalent cases of HIV and AIDS have increased steadily.	Colorado, as well as the nation, continues to report significant decreases in AIDS incidence and mortality as a result of anti-HIV drug therapies. While newly diagnosed AIDS cases have remained stable over the past five years, <b>cases of HIV have increased by 15%.</b>
Through March 30, 2000, a cumulative total of 6,800 cases of AIDS and 4,043 AIDS-related deaths have been reported. An additional 5,597 cases of HIV infection have been reported.	As of June 2004, a cumulative total of 8,155 cases of AIDS and 4,775 AIDS-related deaths have been reported. An additional 6,360 cases of HIV have been reported in Colorado.
Compared to eastern and southern US and to larger metropolitan areas, the epidemic in Colorado is still overwhelmingly driven by sexual exposure, primarily among men who have sex with men (MSM), which continues to be the most significant risk group (at 74% of new HIV or AIDS cases) for males. Among females, the impact of injecting drug use (IDU) is unquestionable, with 54% of new AIDS or HIV cases in females related either directly (30%) or indirectly, through sexual contact (22%), to the use of drugs by injection.	The HIV epidemic in Colorado continues to consist primarily of men who have sex with men (MSM) and men who have sex with men who are also injection drug users (MSM/IDUs). Together these groups comprise over 75% of the cumulative cases of HIV and AIDS. <b>Females represent an increasing proportion of newly diagnosed HIV cases, now accounting for 10% of persons living with HIV and AIDS.</b> Heterosexual contact is the highest risk factor for females, accounting for 58% of all cases among women. By comparison, the numbers of female IDU cases has declined by 47% over the past five years.
In the last three years, only one case of perinatally acquired HIV infection has been reported in an infant born to a HIV-infected mother in Colorado. This success is attributed to the widespread screening of pregnant women for HIV and the use of antiviral drugs during and after pregnancy, labor and delivery.	The number of infants born to HIV-infected women in Colorado peaked in 2000 with 29 births. In 2003, this number declined to 21 births and <b>no infants were reported to have acquired HIV perinatally.</b> The widespread use of anti-retrovirals during pregnancy, labor and delivery is credited with this success.
In Colorado, Whites represent 72% of HIV/AIDS cases, while Blacks and Hispanics represent 14% each of the prevalent cases of HIV in Colorado. Although Whites comprise the largest number of both AIDS and HIV cases, when population rates are compared, both	Racial and ethnic minorities in Colorado have been disproportionately affected by the HIV/AIDS epidemic, compared to other groups. <b>Blacks in Colorado are over represented in the HIV epidemic of HIV/AIDS, particularly among recently infected persons.</b> Their rates of HIV

<sup>13</sup> Colorado Department of Public Health and Environment (2005) *HIV & AIDS in Colorado*, Integrated Epidemiologic Profile of HIV and AIDS Prevention and Care Planning reported through June 2004.

<p>Blacks and Hispanics are disproportionately affected by the epidemic.</p>	<p>infection are four times those of Whites <b>while the HIV rate for Hispanics is one and a half times that of Whites. Racial differences among females are even more profound</b> with Black females over 24 times more likely and Hispanic females three times more likely to be HIV infected than White females.</p>
<p>Nearly 50% of new Colorado AIDS cases were between 30-39 years of age. Additionally, 40% of these cases were in the age range of 25-29 and 40-59 years of age. MSM, ages 20-29 are over represented among recently diagnosed HIV cases; males in this age group account for 16% of the male population but represent 24% of the epidemic.</p>	<p>Through 2004, 43% of persons living with HIV/AIDS were between 30 and 39 years of age, followed by 30% between 20 and 29. <b>Over a third (37%) of newly diagnosed cases were 30-39 years old, while 30% were 20-29. MSMs between the ages of 30-39 continue to be over represented among newly diagnosed cases of HIV</b>, despite recent decreases in the number of new cases reported.</p>
<p>Through March 31, 2000, a cumulative total of 1,516 cases of AIDS and 1,115 cases of HIV infection were associated with injection drug use (either IDU by patient, MSM/IDU, or sex with an IDU). Of these 81% were men and 19% were women. Of recently diagnosed HIV cases among persons who report injecting drug use, ethnic minorities are over represented based on their proportion of the state's population, representing 59% of new HIV cases.</p>	<p><b>Injection drug users (IDUs) represent 10% of the total HIV/AIDS cases reported in Colorado, a 23% increase over the past five years.</b> Through June 30, 2003, there were a cumulative total of 1,868 cases of AIDS and 1,354 cases of HIV associated with IDU. Of these 81% were men and 19% were women. Injection drug use is a disproportionate risk factor for Blacks and Hispanics. Among IDUs living with HIV diagnosed between 2002-2003, 47% were ethnic minorities.</p>
<p>The Denver EMA comprises 79.5% of all cumulative cases while the Greater Consortia Area makes up 20.5% of all cumulative cases. Consequently counting Boulder, El Paso and Larimer counties as part of the Greater Consortium Area.</p>	<p>Within Colorado, the HIV epidemic is concentrated in the Front Range counties (and population centers) of Adams, Arapahoe, Boulder, Broomfield, Denver, Douglas, El Paso and Jefferson where 88% of those with HIV/AIDS live.</p>

## **B. DESCRIPTION OF DATA AND INFORMATION USED IN THE PROCESS**

Colorado Department of Public Health and Environment (2005) *HIV & AIDS in Colorado, Integrated Epidemiologic Profile of HIV and AIDS Prevention and Care Planning* reported through June 2004. (Author) Denver, Colorado.

Colorado Department of Public Health and Environment (2004) *Coloradoans Working Together - Prioritized Population Estimates, 2004*. (Author) Denver, Colorado.

Research & Evaluation Unit, (2003) *Coloradoans Working Together 2002 – 2003 Needs Assessment Report*. Colorado Department of Public Health & Environment  
Denver, Colorado

Denver HIV Resources Planning Council (2005) *2005 Needs Assessment Summary*. Denver, Colorado.

Evaluation and Assessment Committee, Denver HIV Resources Planning Council (2006) *2006-2008 Comprehensive Plan Ryan White Title I, Denver Eligible Metropolitan Area*. Developed in conjunction with the Mayor's Office of HIV Resources. Denver, Colorado.

Research and Evaluation Unit, STD/HIV Section (2005) *HIV PREVENTION IN COLORADO 2003 – 2004: AN ASSESSMENT OF NEEDS*. An Addendum to the 2002 – 2003 Needs Assessment Report for Coloradoans Working Together: Preventing HIV/AIDS. (Author) Colorado Department of Public Health and Environment. Denver, Colorado

**C. INVENTORY OF AVAILABLE RESOURCES IN THE STATE  
(FUNDS AND SERVICES)**

## D. RECOMMENDATIONS FOR DEALING WITH CROSS-CUTTING ISSUES

ROUNDTABLE TOPIC 11/7 SCSN Consensus Meeting	Selected Comments from the SCSN SURVEY	AGENCY/ORG
Colorado's current system of services is difficult for clients to navigate, according to representatives from all Titles funded under the Ryan White CARE Act.	<i>Look at red tape requirements that lack a "common sense" approach</i>	Hospice - Mesa
The presence of many different agencies, some providing overlapping services, complicate how clients receive care. Agencies need to make additional efforts to maintain contact with clients and to track when they require follow up services, sharing client data and referral information across agencies. Better linkages should also be created between prevention and service programs.	<p><i>Patient focused comprehensive care models that include a team-based approach. This not only benefits quality of life, but also financially is so beneficial.</i></p> <p><i>Need for cross-referral network</i></p> <p><i>Solutions on how to better serve more people with less money year after year.</i></p> <p><i>Treatment and prevention services should work more closely together. They tend to be very protective of "their" respective clients.</i></p> <p><i>Prevention is so important!</i></p>	<p>Title III – Boulder</p> <p>DAYS - Denver</p> <p>Denver Health</p> <p>Case Manager - Denver</p> <p>WestCAP</p>
<p>Agencies lack the capacity to coordinate client needs in areas such as adherence to medications, in part due to the confidentiality of client information. A lack of transportation options poses challenges as well. Additional barriers complicating efforts to create a more seamless system include:</p> <ul style="list-style-type: none"> <li>➤ Unfunded mandates requiring that services be provided without any additional funds</li> <li>➤ The absence of one-stop service centers that would improve access to services.</li> <li>➤ Red tape that limits client access to needed services</li> <li>➤ The marginalization of some clients, inhibiting their access to treatment and</li> <li>➤ Communication patterns that are inappropriate for a client's educational level or cultural background</li> </ul>	<p><i>(Create) a database of HIV resources that is readily accessible. Provide comprehensive and affordable health insurance for all!</i></p> <p><i>(Create) culturally sensitive substance abuse programs</i></p>	<p>University Hospital</p> <p>Denver service provider</p>



<p>Coordination of services is a particular challenge for subgroups of PLWH/As including youth, women, minorities and people who are co-infected with HIV and hepatitis C. (Survey results)</p> <p>Agencies need to be more open with clients about the limitations of the current system while becoming creative about addressing them, developing programs that better fit the needs of individual clients.</p>	<p><i>Addressing women, minority prevention: moving to “medical model” and support services not being funded or underfunded (e.g. Housing, transportation)</i></p> <p><i>Funding for minorities and rural patients to access care</i></p> <p><i>Issues related to pregnancy and HIV – preventing perinatal transmission of HIV. Transition services for youth into adult care</i></p> <p><i>Lack of options for undocumented immigrants</i></p>	<p>WCAP – Mesa</p> <p>Case Manager</p> <p>Title IV</p> <p>Advocate</p>
<p>Across all Titles, program staff have identified specific services where gaps and unmet need exist.</p> <ul style="list-style-type: none"> <li>➤ Auxiliary Services such as substance abuse and mental health need to be incorporated into all programs serving PLWH/As, in particular to meet the needs of subpopulations who have not previously been receiving treatment.</li> </ul>	<p><i>I feel I cannot stress the importance of prescription drug coverage and mental health/substance abuse assistance. We struggle daily with these issues.</i></p>	<p>Title III - Boulder</p>
<ul style="list-style-type: none"> <li>➤ Clients have difficulty accessing housing, food, and financial assistance. Program representatives from all Titles need to provide better access to these services and encourage referrals across programs.</li> </ul>	<p><i>We need harm/risk reduction programs for our high needs clients. Housing first programs so we can work with our clients and allow us to work from a client-centered/harm/risk reduction (perspective) in an effective manner.</i></p> <p><i>Ensuring broad spectrum of coverage and services for all PLWH/A in Colorado to allow clients to move up Maslow’s hierarchy (if capable and not limited by funding constraints) instead of wallowing on the ground level. Flat or decreased funding with increased numbers will quickly overburden current system.</i></p> <p><i>More housing options that address substance abuse, mental illness and HIV</i></p> <p><i>Housing needs for PWAs should be more detailed/known</i></p>	<p>Case Manager</p> <p>Mesa – Care program</p> <p>MHCD – Denver</p> <p>PLWH/A</p>

<p>➤ Initiatives to enable clients to get back to work should be developed, including vocational training.</p>		
<p>To address these challenges, representatives from all Titles funded under the Ryan White CARE Act recognize a need to share information regarding gaps in services and unmet need among PLWH/As. Four specific actions were recommended to enhance inter-Title collaboration in the future:</p> <p>Work will be undertaken to create a consistent methodology for defining gaps and unmet needs in services.</p>	<p><i>Collaboration to determine and quantify unmet need -- need dialogue among RWCA programs</i></p> <p><i>Need better collaboration to more accurately quantify unmet need; more effective use of state data base</i></p>	<p>Title I</p> <p>AETC</p>
<p>The Title II program (Colorado Department of Public Health and Environment) will reconvene staff representing all Titles to plan for a statewide needs assessment. Others to be included will be representatives from <i>Coloradoans Working Together</i>, the Prevention Planning Council. Participation by consortium area staff throughout the state will help to ensure that differences between the urban and rural parts of the state are considered in the needs assessment process.</p>	<p><i>A statewide consortium of agencies and individuals providing care and services to PLWH should be formed. This collective should meet once a year (at least) in a statewide initiative to network, partner and collaborate; form sub-groups to address specific issues.</i></p> <p><i>Rural areas though not high prevalence areas for HIV, continue to need prevention and case management funding to retain visibility within the communities as well as provide timely and local assistance to PLWH.</i></p> <p><i>Extreme rural areas cannot access Title programs in a reasonable manner. Also, Title IV (CHIP) does not offer clinics in any place except Denver. Some clients suffer due to lack of access.</i></p> <p><i>I'm concerned about rural areas. I am hearing of people who live there that are gay that are fearful of their safety asking for this type of assistance.</i></p>	<p>Early intervention services – Pueblo</p> <p>Alamosa - AHEC</p> <p>NCAP</p> <p>PLWH/A</p>
<p>Staff from all Titles will share research information across programs. For example, when CDPHE does special research projects, these results will be available to other programs for review.</p>	<p><i>Share needs assessment results (do Title III and Title IV do needs assessments?) Better collaboration between Title II, Title III and Title I.</i></p>	<p>AETC</p>

Collaborative efforts will be undertaken to document what's working in the Title I, Title II, Title III, and ADAP programs, documenting and sharing "program successes."	<i>A more realistic and honest look at the ADAP program, i.e., better accountability of funding. Stop the "sky is falling" mentality and realize ADAP is not the "sacred cow!"</i>	PLWH/A
<ul style="list-style-type: none"> <li>➤ Determine how to better leverage Title II CARE dollars with other funding sources such as prevention programs sponsored by the Centers for Disease Control (CDC), the National Institutes of Health (NIH) and the Substance Abuse and Mental Health Services Administration (SAMHSA).</li> </ul>	<p><i>Collaboration to develop resources outside of RWCA funded continuum -- need dialogue among RWCA programs</i></p> <p><i>Gaining governmental support and knowing political/government structure to better tap into the resources, which control the funds that in turn control the channeling and allocation of funds.</i></p>	<p>Title I</p> <p>Advocate</p>
<ul style="list-style-type: none"> <li>➤ Collaborate with mental health agencies, leveraging non-Ryan White sources of service dollars</li> </ul>	<i>HIV does not happen in a vacuum. People need mental health help to address all their life issues. This is preventative medicine and it is cost-effective.</i>	Denver Advocate
<ul style="list-style-type: none"> <li>➤ Use the 340B option to buy cheaper drugs, creating access for clients to gain access to non-ADAP formulary drugs.</li> </ul>		
<ul style="list-style-type: none"> <li>➤ Coordinate efforts across agencies need to ensure that clients are not lost in the new Medicare Drug Plan Process under Medicare Part D.</li> </ul>	<p><i>Meds! Medicare Part D is telling clients with incomes that aren't on Federal levels they need to choose food or meds and if meds which ones – or die!</i></p> <p><i>Medicare Part D – Implementation coming and options and information being relayed is not consistent – making good personal, financial and health plan choices difficult.</i></p>	<p>PLWH/A</p> <p>PLWH/A</p>

## E. DESCRIPTION OF PROCESS USED TO DEVELOP THE SCSN

Colorado's SCSN has been focused on identifying crosscutting issues for the individual Ryan White CARE Act and Part F programs. Targeted priority areas have been identified from multiple sources including existing needs assessments, epidemiological data sources, face-to-face meetings, a widely distributed survey and a consensus meeting of key HIV/AIDS stakeholders in the state. Information from the State's Unmet need calculation has been included which identifies the numbers of persons who know their HIV status but are not in care. Finally, critical gaps in life-extending care needed by PLWH both in and out of care have been identified.

Following guidance from the Health Resources and Services Administration (HRSA), the following process were followed in developing Colorado's Statewide Coordinated Statement of Need (SCSN):

### **Representative Process**

The process of developing the SCSN included:

All Ryan White CARE Act Grant recipients and the Administrator of the AIDS Education and Training Centers

Title I Grantee representatives and Planning Council representatives

Title II Consortia and grantee representatives

Persons living with HIV/AIDS

Providers receiving Ryan White funds or providing services to PLWH/As

Public Agency Representatives and

Other providers or funders of services for PLWH/As such as Substance Abuse, Mental Health, Medicaid and Medicare, Veteran's Administration and Community Health Centers.

### **Process for Developing the SCSN**

Copies of relevant plans and needs assessments were obtained. (See Appendix C.)

An inventory of CARE Act resources in the State was created.

Comparisons were made of epidemiological trends between 2001 and 2005

One-on-one interview and outreach efforts were conducted with the Title I, Title III, Title IV, and AETC directors.

A survey seeking input on emerging trends, service gaps and cross-cutting issues was broadly distributed; 195 responses were obtained.<sup>14</sup>

The Title II grantee convened a meeting with cross Title representatives who defined themes for the SCSN on November 7. Invitations were broadly distributed and 23 representatives from Colorado's HIV/AIDS community participated.

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<sup>14</sup> The survey containing both close and open-ended survey options was distributed over a four-month period through various CDPHE HIV listservs, to all Ryan White CARE Act program representatives and through the Title II consortia. Respondents could return their responses by mail or fax. An Internet version of the survey was also made available.